



DISABILITY NOTES

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FROM THE ASSOCIATE COMMISSIONER:

This will be my last message to you. After more than 30 years of service to SSA, I have decided to retire.

Over the course of my career, I have had the opportunity to work in many different positions throughout SSA and to meet many dedicated civil servants. I can sincerely say that my tenure in the Office of Disability has been the most professionally satisfying and the most personally interesting and stimulating. I am very proud to have had a leadership role in Social Security's disability programs and am proud to have had the opportunity to work with the many dedicated individuals in the federal and state governments who bring SSA's disability programs to the American public.

It has also been an honor to work with so many of you in the disability community. I know many of you personally and have had the opportunity to obtain your perspectives on issues of mutual interest and to learn about your experiences (good and bad!) with the disability programs.

It has been a challenging and fulfilling experience. We can take great pride in

what we have accomplished together. We all know that more still needs to be done—I am confident that with your help my successor will build on those accomplishments.

Ken Nibali

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SECOND NATIONAL DIALOGUE ON CHILDHOOD DISABILITY -A SUCCESS

Researchers, policy analysts and program administrators met with community groups and families to discuss trends in childhood disability programs March 14-15 in Washington, DC. The co-chairs, Stephanie Smith Lee, Office of Special Education Programs, Department of Education, and Eileen Sweeney, Center on Budget and Policy Priorities, brought together an ambitious agenda with sessions covering such issues as:

- Accessing medical care and quality health care services
- Income and resources reporting
- Educating the teacher community on SSA's definition of disability
- Gathering and securing the best possible information about the child's impairments.

One of the major highlights of the conference was a speech by SSA Commissioner Joanne Barnhart. She noted the conference was one of many ways "to talk and to strengthen our relationships with the disability community and the families and children that we serve."

A central goal of this conference was to ensure that children with disabilities receive all of the benefits they're eligible for under the law and that benefits are paid only to children who meet the SSI program's strict definition of disability.

THE DEFINITION AND EVALUATION OF DISABILITY FOR CHILDREN FILING FOR SSI BENEFITS

Like the definition for adults under the Title II program, the definition of disability for children under the Title XVI program-- SSI--is found both in statute and regulations. A child under the age of 18 is disabled if he or she has a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations and that can be expected to cause death or has lasted or can be expected to last for a continuous period of not less than 12 months.

The evaluation process to determine disability under the above definition assesses whether the child's impairment or combination of impairments results in marked and severe functional limitations. There are three steps in the evaluation process.

Step One. Is the child performing substantial gainful activity (SGA)?

Just like in the adult rules, if a child is working and the work is SGA, the child is not disabled. If the child is not engaged in SGA, we proceed to Step 2.

Step Two. Does the child have a severe impairment or combination of impairments that is severe?

- a. "Severe" means that an impairment or combination of impairments has more than a minimal impact on a child's functioning.

- b. At this step, we consider the combined effects of all a child's physical or mental impairments.

If the child does not have a "severe" impairment(s), disability is not established. If the child does have a severe impairment(s), we proceed to Step 3.

Step Three. Does the child's impairment meet, or medically or functionally equal, the severity of a listing?

SSA maintains a listing of impairments. These listings cover the major body systems and include descriptions of physical and mental impairments (such as cerebral palsy, mental retardation) along with specific medical severity criteria. The listings can be found in Title 20 of the Code of Federal Regulations in Appendix 1 to subpart P of part 404. (Note: Part B of the appendix exclusively applies to the evaluation of impairments in children.) You can find the listings on SSA's web page at: http://www.ssa.gov/OP_Home/cfr20/404/404-ap09.htm. If the child's impairment or combination of impairments meets the criteria of a listing and lasts long enough, the child meets the definition of disability.

If the child's impairment or combination of impairments does not meet any of the listings the child may meet the definition of disability by *medically equaling* a listing. To medically equal the listings, an impairment or combination of impairment must be of equal medical severity to a listed impairment.

If the child's impairment or combination of impairments does not meet or medically equal any listing, the child can still qualify if his or her impairment(s) *functionally equals* the listings. To functionally equal the listings, an impairment or combination of impairments must be of "listing-level severity"; i.e., it must result in marked limitations in two domains of functioning or extreme limitation in one domain.

We use the following six domains:

- **Acquiring and using information.** In this domain, we consider how well the child acquires or learns information and how well he/she uses the information learned.
- **Attending and completing tasks.** In this domain, we consider how well the child is able to focus and maintain attention and how well he/she begins, carries through and finishes activities, including the pace at which the activities are performed and the ease with which the child changes them.
- **Interacting and relating with others.** In this domain, we consider how well the child initiates and sustains emotional connections with others, develops and uses the language of his/her community, cooperates with others, complies with rules, responds to criticism and respects and takes care of possessions of others.

- **Moving about and manipulation objects.** In this domain, we consider how the child moves his/her body from one place to another and how he/she moves and manipulates things. These are called gross and fine motor skills.
- **Caring for yourself.** In this domain, we consider how well the child maintains a healthy emotional and physical state, including how well the child copes with changes in his/her environment and whether he/she takes care of his/her own health, possessions and living area.
- **Health and physical well-being.** In this domain, we consider the cumulative physical effects of physical or mental impairments and of their associated treatments or therapies on the child's functioning that we did not consider in the "moving about and manipulating objects" domain. When the child's physical impairment(s), mental impairment(s) or combination of physical and mental impairments has physical effects that cause "extreme" limitation in his/her functioning, the child will generally have an impairment(s) that "meets" or "medically equals" a listing.

If you want a detailed description of the process and the requirements for entitlement, we suggest you read sections of 20 CFR 416.906 , 416.924 ff. These sections can be found on the SSA web site at

http://www.ssa.gov/OP_Home/cfr20/416/416-0000.htm.

REQUESTING INFORMATION FROM SCHOOLS AND TEACHERS

Information from schools and teachers is often very important in determining whether a child meets the definition of disability. This coming school year, the State Disability Determination Services (DDSs) will be using a new form, appropriately titled "Teacher Questionnaire" (TQ), (Form SSA-5665-BK) to request information from these vital sources. The TQ, together with the related "Request for Administrative Information" (Form SSA - 5666), will be accompanied by a signed authorization from the parent or legal guardian for the disclosure of information. The signed authorization form, "Supplement to Form SSA-827 For Use in Cases of School-Age Children," was developed to comply with the laws that govern whether schools can supply information, particularly the Family Educational Rights and Privacy Act (FERPA), and the U. S. Department of Education regulations.

Teachers and others in the education profession are very busy. We worked very hard during the development of these forms with educators and with the Department of Education to make the TQ easy to understand, navigate and complete. The form employs a consistently clear numeric rating system - many questions may be answered by circling the applicable rating number. The form is designed to get a picture of the child's day-to-day functioning in school and the child's functioning

compared to that of other children the same age who do not have impairments.

The TQ (Form SSA-5665-BK) and “Request for Administrative Information” (Form SSA - 5666) can be reviewed and downloaded and /or printed from the SSA web site at: <http://www.ssa.gov/online/forms.html>. Once at this site enter *Form Number* in the “Search” block and the form number in the “For” block.

If you want more information or have a question about the TQ form, the Professional/Medical Relations Officers in the DDS in your state can help. You can find a complete list on the web at: <http://www.ssa.gov/disability/professionals/procontacts.htm>.

PROTOTYPE UPDATE

As we have reported in prior issues of *Disability Notes*, SSA has been conducting prototypes – tests of changes to the way disability applications are processed. (For more background, check out: <http://www.ssa.gov/disability/disabilitynotes>.)

SSA has been conducting a prototype of a combination of redesign features in ten States: New Hampshire, Pennsylvania, New York, Alabama, Louisiana, Michigan, Missouri, Colorado, California, Arkansas. These features include:

- Giving disability examiners (commonly referred to as single decisionmaker or SDMs) the authority to make decisions independently in most cases.

- Providing the claimant the opportunity in less than fully favorable cases to speak with the decisionmaker about their case (a claimant conference).
- Eliminating the reconsideration step of the appeal process.

The SDM feature enables the medical and psychological consultants to act as true consultants, and also frees up time for them to provide training and mentoring to the examiners as well. The elimination of the reconsideration step provides the resources for more complete development and improved explanations of how the disability determination is made in order to enhance the quality of decisions.

We have been doing the prototype since October 1999. We found that while the prototype process had some good results in terms of better initial decision making and more efficient use of DDS adjudicative resources, overall it did not accomplish what we had hoped it would.

Based on what we have learned, the Commissioner has decided that we cannot implement the prototype process as it exists, but she has decided to pursue the nationwide expansion of the single decisionmaker feature to make the most effective use of examiner and medical and psychological consultant resources.

Implementing SDM authority nationwide will result in more effective use of examiner and medical and psychological consultant resources. SSA must publish a final regulation in the Federal Register before national expansion of the SDM, which we expect to do this summer.

When the current prototype authority expires in June we will no longer be testing the claimant conference. Instead, SSA will encourage early and ongoing contact with the claimant when appropriate. The end-of-line conference added processing time, and was not as effective as we had hoped. Most States that have been participating in the prototype found early and ongoing contact with the claimant to be more effective.

We also intend to extend the authority for elimination of the reconsideration step in the ten states as we consider broader issues related to the entire claim process and any changes that need to be made.

You can check on regulations for these proposed changes in the upcoming months on the web at:
<http://policy.ssa.gov/pnpublic.nsf/LawsRegs>

These steps affirm the Commissioner's words before the Subcommittee on Social Security of the House Ways and Means Committee on May 2, 2002: "I feel very strongly that we must move forward now and make decisions on what we can do immediately to improve disability processing while laying the groundwork for additional mid- and longer-term improvements."

EVALUATING HEMATOLOGICAL DISORDERS AND MALIGNANT NEOPLASTIC DISEASES

We reopened the comment period for the notice of proposed rulemaking (NPRM) we published in the Federal Register (66 FR 59306) on November 27, 2001. The

reopened NPRM describes how we propose to revise the hematological disorders and malignant neoplastic disease listings

Comments that we had received during the rulemaking period raised significant issues; therefore we decided to provide an additional 60-day public comment period for these rules beginning April 18th, 2002. During this time we met with a number of key advocates. You can review the meeting proceedings on the web at:

<http://policy.ssa.gov/erm/rules.nsf/Rules+Open+To+Comment>.

The update of this listing is part of our initiative to update all of the listings.

MEDICARE SAVINGS PROGRAMS – YOU MAY QUALIFY

Studies have shown that millions of Americans may be eligible for programs called "Medicare Savings Programs" but are not taking advantage of them.

"Medicare Savings Programs" is an umbrella name given to the Qualified Medicare Beneficiary (QMB), Specified Low-Income Medicare Beneficiary (SLMB), Qualifying Individual (QI) and Qualified Disabled and Working Individual (QDWI) programs. These state-administered Medicaid programs subsidize certain Medicare expenses for beneficiaries with limited means. Under the authority of a recently enacted provision of the Social Security Act, SSA is identifying potential Medicare Savings Program eligible individuals. SSA will share the list of potential

eligible individuals with state Medicaid agencies.

In addition, from May 10 to November 8, nearly 16.5 million potentially eligible individuals will be sent a letter alerting them to their potential eligibility for QMB/SLMB/QI benefits. The letters encourage them to contact the state agency administering Medicaid if they believe they meet eligibility criteria described in the letter or have questions. These programs pay the Medicare Part B premium, now usually \$54 per month. The QMB program also pays other Medicare-related expenses.

Letters to individuals who may be eligible as QDWIs will be mailed the last week of November. After contacting their state Medicaid agencies, potentially eligible QDWIs no longer in their initial enrollment period will need to file a Medicare application with SSA as a disabled and working individual during the January-March General Enrollment Period. The QDWI program pays the Medicare Part A premium. The monthly premium is either \$175 or \$319 per month. The premium amount depends on the individuals work history.

The outreach letters vary from state-to-state to reflect different State contact information and variations in State eligibility rules.

If you or someone you know receives one of these letters, we encourage you to act on it and check out eligibility for these programs.

THE TICKET TO WORK PROGRAM

The Ticket to Work and Self-Sufficiency Program (Ticket to Work Program) was established by the Ticket to Work and Work Incentives Improvement Act of 1999. It assists Social Security and Supplemental Security beneficiaries with disabilities to obtain, regain and maintain self-supporting employment by expanding their choice of employment services, vocational rehabilitation services and other support services.

Phase one of the ticket rollout is underway and over 1.2 million tickets have been mailed to beneficiaries with disabilities in Arizona, Illinois, Oklahoma, Wisconsin, Colorado, Iowa, Oregon, Delaware, Massachusetts, South Carolina, Florida, New York and Vermont.

To date beneficiaries have assigned over 2,400 tickets to Employment Networks and to state vocational rehabilitation agencies.

SSA has approved over 400 applications from organizations seeking to serve as Employment Networks. MAXIMUS, the Ticket to Work Program manager, is sponsoring free Employment Network Recruitment Conferences around the country. Any state or local agency or private organization that is qualified to provide services to beneficiaries with disabilities can apply to be an Employment Network. For a complete listing of future employment network conferences, visit MAXIMUS' web site at www.yourtickettowork.com or call toll free 1-866-968-7842 or the toll free TDD Line 1-866-833-2967.

Phase Two of the ticket mailings will begin later in 2002. Tickets will be mailed to over 2.7 million beneficiaries with disabilities in Alaska, Arkansas, Connecticut, Georgia, Indiana, Kansas, Kentucky, Louisiana, Michigan, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, South Dakota, Tennessee, Virginia and the District of Columbia. Employment network application requests are now being accepted from Phase Two States.

In 2003, during the third and final phase, SSA will mail tickets to beneficiaries with disabilities in the following States and territories: Alabama, California, Hawaii, Idaho, Maine, Maryland, Minnesota, Nebraska, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Utah, Washington, West Virginia, Wyoming, American Samoa, Guam, Northern Mariana Islands, Puerto Rico and the Virgin Islands.

For more information on the Ticket to Work Program and other employment support programs for beneficiaries with disabilities, visit the Office of Employment Support Programs' "WorkSite" at <http://www.ssa.gov/work>.

EDITOR'S NOTE

In Search of your Ideas and Materials

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